

Michigan Family Connections Newsletter

Summer 2017

SEEKING FAMILY LEADERS

We are pleased to announce that the Family Center for Children and Youth with Special Health Care Needs (Family Center) and the Michigan Family to Family Health Information Center (Family to Family) are looking for individuals to serve on our **Family Leadership Network (FLN)**.

In recognition of the importance of family involvement, the FLN was created out of the common need to obtain diverse perspectives from families and receive input on programs and special projects. Family perspectives are highly valued and contribute to a better understanding of experiences with healthcare and other systems in Michigan.

We are looking for individuals who have personal experience as a parent, guardian or caregiver of a child or young adult (up to age 26) with a disability or other special needs; or be a young adult (18 or older) with a disability or other special needs. We are seeking two members from each one of the [Michigan Prosperity Map Regions](#).

Some of the responsibilities of this position include:

- Participating in quarterly meetings including a yearly in-person meeting/training
- Identifying local community partners and resources available to families who have children and young adults with special health care needs (CYSHCN)
- Listen to feedback from families in your region so that you can represent a regional voice in the FLN on programs, priorities, and initiatives
- Encourage families in your region to use resources and activities sponsored by the Family Center and Family to Family

(For more information including the Position Description and Operating Guidelines, please see the Family Leadership Network Information Packet available [here](#).)

Are you able to share your personal experience in a way that informs and empowers others? Do you have the desire to grow as a family leader? If you do and you have an interest in providing input on important programs and services for families of children and young adults with special health care needs, we need you!

Interested individuals should submit an [application](#) by July 28th.

If you have questions or would like an application mailed to you, please call the Family Phone Line at 800-359-3722



*A newsletter
for families of
children and youth
with special health
care needs, and
professionals who
help them.
Connecting you
with information
and news you
can use!*



**A quarterly publication
brought to you by the
Family Center for Children
and Youth with Special
Health Care Needs and
Michigan Family to Family
Health Information Center**



SICKLE CELL PATIENTS—GET CONNECTED!

A national effort to enhance the quality of life for patients living with sickle cell disease is the new **Get Connected**. It is a confidential, patient-powered registry housed at and managed by the Sickle Cell Disease Association of America (SCDAA). The registry helps create a more involved and knowledgeable community.

The registry houses basic information, and allows individuals to keep their medical history secured and up-to-date in one electronic location. The registry distributes a newsletter, has patient community forums, and shares sickle cell disease specific information.

Maintaining a national patient registry where all can patients stay up-to-date and maintain their medical histories

helps create better health care solutions for all individuals with sickle cell disease. This resource also helps parents understand their baby's newborn screening diagnosis and how it impacts their family.

Get Connected allows the SCDAA to get aggregate level data from patient entries, such as getting an overview of how many individuals living with sickle cell disease reside in the United States. This pertinent data can be used to request support for research and treatment funding. There is power in numbers so help the Michigan sickle cell community to be well represented!

You can register for free at:
www.GetConnectedscd.org

“When a flower doesn’t bloom, you fix the environment in which it grows, not the flower.” - Alexander Den Heijer

LEARN THE SIGNS—ACT EARLY

The CDC estimates that 1 in 68 children has been identified with an autism spectrum disorder and about 1 in 6 children aged 3-17 has a developmental disability. Many children with a developmental disability are not identified until after entering school. Early intervention (before school age) can have a significant impact on a child's ability to learn new skills as well as reduce the need for costly interventions over time.

The Family Center is excited to collaborate with the CDC's "Learn the Signs. Act Early" program. This program offers free, parent-friendly tools to promote awareness of healthy developmental milestones in early childhood. It encourages parents to track their child's development and stresses the importance of acting early if there are concerns. As an "Act Early Ambassador", the Family Center is promoting the program's messages and tools and helping to improve early identification and intervention efforts in Michigan.

From milestone checklists and information to training and free materials, the "Learn the Signs. Act Early" website offers numerous research-based tools to track your child's development and celebrate your child's milestones. Acting early can make a real difference! For more about what to do if you have a concern, visit the [If You Are Concerned](#) page.

For more information about CDC's "Learn the Signs. Act Early" visit the website at <https://www.cdc.gov/ncbddd/actearly/index.html>





SPOTLIGHT ON THE EPILEPSY FOUNDATION OF MI

Epilepsy Foundation of Michigan provides a variety of services to support children with epilepsy, family members, and professionals who serve them. Please contact them to enlist their help in any of the following areas:

School Services (provided on-site by our Education & Advocacy Specialist – a licensed RN)

- Seizure recognition & first aid training for staff
- Hands-on rescue medication training
- Assistance with seizure response training
- Advocacy (e.g. help with IEP and 504) planning

Training for Other Professional Audiences

- Local health departments
- Federally Qualified Health Centers
- Medicaid managed care plans
- First responders
- Summer camps
- Day care centers

Education and Support for Patients and Families

- Tailored workshops on topics such as...
 - ◆ Epilepsy diagnosis and treatment
 - ◆ Epilepsy self-management
 - ◆ Epilepsy and school performance
 - ◆ Transition
- Facilitated discussion groups for parents and teens
- *Camp Discovery** – 5-day summer camp for children with epilepsy ages 8 – 17; includes 24-hour medical staffing
- *Learn & Share Conference Calls* – educational conference calls featuring a different epilepsy-related topic and speaker each month
- *Wellness & Epilepsy Conference** – annual conference featuring a keynote address, presentations and panel discussions, networking time, and a day camp for kids
- *Here for You Helpline* – individualized consultation by phone, email, or face-to-face meeting

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Education & Advocacy Specialist

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**Fees are charged for these programs, but financial assistance is available. No one is turned away due to inability to pay.*

A FATHER'S PERSPECTIVE

In this edition, we feature an interview with a father, Jim Pantelas. In it, he shares his thoughts on some of the joys and challenges of having a daughter with special health care needs.

My daughter, Stella, 11, had a brain bleed at 21 days old. It was touch and go for the first couple of months of her life, but while she was pretty severely injured by the incident, she is the light of our lives. Her laughter is contagious, and her smiles warm our hearts. She has two younger sisters, ages 9 and 7. That makes us a very busy family of five.

We remain frequent fliers at Mott Children's Hospital and Stella sees many specialists. Stella isn't verbal, so anticipating her needs is an ongoing issue. But she goes to school, has relationships, has a sense of humor, and participates in everything we do as a family.

I knew I'd need as much help as I could get to understand her evolving needs, so I started volunteering at Mott on a Continuum of Care Committee. Within six months I was asked to participate on their Pediatric Ethics Committee – a committee I continue to sit on ten-plus years later!

Navigating the world of special needs is like living in a country where they speak a language you don't know. Finding interpreters is imperative, and, to me, volunteering was a way of finding those people. It was also a way for me to share what I was learning with others.

One of the biggest challenges we face is I don't think the pediatric health care world knows how to deal with fathers all that well. The primary care giver for children is often assumed to be the mother. I am very involved in Stella's care, and an equal when it comes to her medical care. Because of that, a big part of my involvement with any particular provider is initially spent in defining my involvement so that I am not discounted.

There are also the challenges you face on a day-to-day basis. Not knowing that your child's first wheelchair would weigh so much, not fold up, and would necessitate a massive conversion to the family van to take her anywhere. Not knowing that soluble tablets work differently if they're crushed. And a whole host of things you learn and have to learn daily!

And finally, there are the challenges of just seeing the world through your own perspective while the world seems to expect a family to have a joint perspective. My wife and I don't always agree, and, in fact, have had very different perceptions of



Stella's condition and needs over the past 11 years. That doesn't mean that one is right and one is wrong, but it does mean that we can look at the same issue or hear the same conversation and come away with very different understandings of them.

Yes, when you're raising a special needs child there are times of great frustration, and there can be great sadness in those moments just before sleep when you wish your child could do something they will never be able to do, but there are also moments that are joyful and so full of love!

Watching her joy when she dances in her Hopsa*, the joy of seeing her smile when she wakes up, or just the wonder when you see she has strong and meaningful relationships with the kids, teachers and aides at school.

Having a child with special needs creates special times. It's not less than you have with your other children - it's just different. And the inclusion in your life is rich and pretty wonderful. If we could, would we fix our child? Of course we would. That's what dads are meant to do. We fix things. But some things are not fixable, and that can be amazingly hard to get used to. But there is still so much humility, wonder and joy in the unfixable!

These are the things that create our stories and that make them compelling and relatable. The adaptations we make that help us live through the unexpected is the basis for the men we are. Having a special needs child is another unexpected thing in our life. How we adapt to it, how we navigate our lives with this new inclusion will define the fathers we become.

**A harness that allows her to stand in partial weight-bearing mode without pain.*

CONDUCTIVE EDUCATION EVALUATION

Michigan State University's Conductive Education Evaluation Project (CEEP) is a research study offering 2 to 6 year olds with cerebral palsy a free 4-week session at the Conductive Learning Center (CLC) in Grand Rapids. Children also receive several motor skills assessments at Mary Free Bed Rehabilitation Hospital.

Children are enrolled in a session that fits their age and abilities and is convenient for their family's schedule. Enrollment is continuous throughout the year so there is no deadline for participating. CEEP is funded by the Michigan Department of Education.

For more information on who is eligible and how to enroll, go to: <http://www.epi.msu.edu/ceep/>

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HEALTH LITERACY: READING A PRESCRIPTION DRUG LABEL

Medication errors cause at least one death every day and injure approximately 1.3 million people annually in the US. Common errors include: a mix up in product names, hard to read writing, or patient misuse because of not understanding the directions for use. Looking closely at your medication labels can help avoid some of these errors. Here is what you can learn from the label.

Who is the prescription drug for?

This may seem obvious but always check the name on the bottle. You don't want to take someone else's prescription by mistake.

What is the name of the medication?

Drug labels may show the brand name or generic name for the medication, or both. Knowing both names may help prevent accidentally taking a double dose of the same medication. Filling all your prescriptions at the same pharmacy can also help avoid mix ups.

What is in the prescription drug bottle?

The label tells you what form the medicine is in such as tablet (TAB) or capsule (CAP). It will tell you the dose in each. This may be given in milligrams (mgs). It should also say how many are in the bottle. Some pharmacies include a picture or description of the medicine as well. It is a good idea to open the bottle to make sure it matches what the label says. If not, notify the pharmacist right away.

How do you take the prescription drug?

Each pharmacy has its own way of writing directions on the label. How specific they are varies. An example of specific directions would say "take 2 tablets by mouth in

the morning and 2 tablets by mouth 12 hours later" where as "take 4 tablets daily" is less specific. Ask the pharmacist or your doctor if you have questions. Misunderstandings can cause a mistake in how the medicine is taken.

Drug labels also include basic information you need including:

- Prescription number
- Prescribing doctor's name
- Date filled
- Number of refills
- Expiration date
- Warnings
- Pharmacy info

As much as you can learn from reading the prescription label, there is no substitute for talking with your doctor or pharmacist.

If you are unsure about anything, don't hesitate to ask those important questions. Your life or well being may depend on it.



SAVE THE DATE!!

SIBSHOP TRAINING

**Friday, August 25 and
Saturday, August 26, 2017
Spectrum Health Butterworth Hospital,
Grand Rapids MI**

Introduction to Sibshops – Parents, caregivers, service providers, educators, community partners, Local Health Department staff. Attendees who would like to know more about Sibshops and sibling issues, but not interested in how to run a Sibshop would attend day one (Friday).

Adult Sibling Panel – We are searching for 4-7 adults who have a sibling with special needs to participate on a sibling panel held on day one (Friday).

Facilitator Training – Anyone interested in sibling issues, who would like to learn how to run a Sibshop of their own. Attendees interested in becoming a facilitator would attend **both** days (Friday & Saturday) of the Sibshop training.

Demonstration Sibshop – We are searching for 20 young siblings (ages 8 to 13) of children with special needs to join us on day two (Saturday).

For more information on this opportunity, contact the Family Phone Line 800-359-3722



Michigan Family to Family Health Information Center (MI F2F) is a federally funded project. They share information and resources on disability and health issues with families of children and youth with special health care needs. MI F2F also works with health and other professionals. MI F2F helps families make educated decisions and supports families to partner with professionals. They work to make services for children and youth with special health care needs better.



www.f2fmichigan.org



The Family Center for Children and Youth with Special Health Care Needs (Family Center) is the statewide parent-directed center within Children's Special Health Care Services (CSHCS) and the Michigan Department of Health and Human Services (MDHHS). The primary role of the Family Center is to offer emotional support, information and connections to community-based resources to families of children and youth with special health care needs, including all children who have, or are at an increased risk for: physical, developmental, behavioral or emotional conditions.

Family Phone Line 800-359-3722

Disclaimer: The Family Connections newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by the Family Center for Children and Youth with Special Health Care Needs, Michigan Family to Family Health Information Center, or our funders. The Michigan Family to Family Health Information Center is a project of the Michigan Public Health Institute. It is funded by Health Resources Services Administration Maternal and Child Health Bureau under Grant H84MC26214. The information or content and conclusions of the author should not be construed as the official policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. Furthermore, the information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care. Please direct any questions through the Family Phone Line or MI F2F website listed above.